

Submission
No 182

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Name: Name suppressed
Date Received: 7 August 2018

Partially
Confidential

Director Portfolio Committee No.2
Health & Community Services
Legislative Council
Macquarie Street
Sydney, NSW 2000
5 August 2018

Inquiry into the implementation of the National Disability Insurance Scheme and provision of disability services in NSW

Dear Director,

Please place the following submission before the Committee.

In order to explain the submission it is necessary to give personal details of my daughter, _____ who is 46 years of age. I take it that these details will remain confidential other than for the purposes of the Inquiry.

NDIS approval was dated 18 December 2017. The principal circumstance leading to this was a stroke on 14 June 2017, but she has a life long history of medical issues which are summarised on an attachment.

On the day of the stroke she was admitted to _____ Hospital for acute care. On 26 July 2017 she was discharged to _____ Hospital at _____. She was discharged from there on 9 January 2018 to _____ Building _____, a residential care facility in the grounds of the _____

Despite intensive therapy at the _____ Hospital _____ was left unable to walk, talk or eat normally, and that is still the case. Her life is divided between time in a powered wheelchair which she is unable to operate herself, and time in bed. To transfer between wheelchair and bed she must be hoisted. She continues to be fed by peg tube through the stomach. That is also the route for all her numerous medications other than insulin and other injections.

Although the time in _____ Hospital did not produce the desired outcome much good work was done by dedicated professionals, and there were some improvements with hope for more. However the transition from the time she became an NDIS client at _____ was very disappointing.

Prior to discharge from _____ was administered botox injections and had serial casting of limbs over 6 weeks, a difficult and painful procedure. It is vital that the treatment be followed up seamlessly by regular physiotherapy and occupational therapy. However the number of hours allocated by NDIS was inadequate and slow to commence so the benefit of months in rehabilitation were not maximised. The same applied to speech therapy. Alternative ways were

eventually found to get these therapies going but the delays were unhelpful and inexplicable given the relationship between [redacted] and [redacted] which is located within the same grounds.

Another big concern was the minimal NDIS hours allocated to the dietitian. Given that [redacted] life is dependent on tube feeding and that she is insulin dependent and epileptic the importance cannot be overstated.

Both the [redacted] and [redacted] were fully aware of [redacted] complex medical and nursing needs which were documented by them. It was therefore a shock to learn in May 2018 that Registered Nurses were to be removed from [redacted] Building where [redacted] is located. She is only one of a number of clients there with similar complex needs. Oddly enough it was considered necessary to retain registered nursing staff in [redacted] Building where all non NDIS clients were relocated. There can be no doubt that the condition of the clients in both buildings justifies nursing staff.

The rationale for this was explained in a meeting about the new Operation Plan which was presented as a fait accompli without prior consultation. [redacted] management stated that "The Commonwealth Government has determined that it will fund a support worker model of care for people with disabilities, not a nursing model of care".

Effectively this entails support workers doing quasi nursing duties with minimal and hasty on the job training. They are often good people, caring and enthusiastic, but they and the clients would benefit greatly from the presence of a registered nurse on all shifts. I can personally cite specific instances where my daughter has been endangered by inexperience and poor communication.

There are some clients who rarely have a family member visiting to observe such things and others whose carers do not have the knowledge that I do. God help any who do not speak good English, or indeed cannot speak at all. Add to the communication mix the fact that some support workers themselves do not have English as their first language.

At [redacted] Building all support staff report to the accommodation manager, a hard working and conscientious person of whom much is asked. That said the accommodation manager is not on site overnight, nor ordinarily at weekends. At these times decisions will sometimes have to be made as to whether a client needs to be admitted to hospital. There is some sort of protocol in place as to how that decision is made with telephone contact I believe, but in the absence of speedy contact there is no option but to call 000.

The presence of a single registered nurse on all shifts to my mind does not constitute a "nursing model of care, merely basic common sense. An experienced

months. Provision was made for an NDIS funded hoist but it has still not arrived although ordered last year.

On my daughter's behalf I elected to have an NDIS Coordinator mainly to assist with paying bills and hiring support. She is a competent helpful person but is budgeted for less than \$4,000 and works part time. I therefore spend an extraordinary amount of time doing my own coordination of the myriad therapists, GP, external medical specialist appointments, volunteers, transport, NDIS issues, advocacy etc

Even though we have the above mentioned Coordinator I have needed to contact NDIS several times to reconfirm authorisation. Last time it transpired that they had my ID details wrongly recorded. They had my date of birth as January 1999. In fact I shall be 80 years old next birthday. As I am a widower and nominated carer you may deduce that I need to make the best use of my time. I happily spend from 3 to 5 or 6 hours daily visiting my daughter and helping out. I am not so happy that most of the rest of each day is required for dealing with associated email, documentation service agreements etc

I mentioned part time employment of service providers and staff. Nearly everybody I deal with works part time and/or contract and the turnover is high. It can be near impossible to arrange a meeting of key people in my daughter's care at times. Because of their tenuous employment some are understandably reluctant to speak frankly to their managers about misgivings they have about policy implementation. Others though will share with carers exactly the same concerns I have expressed in this submission.

Personally I have been too busy so far to ascertain whether I am eligible for a carer's allowance. My daughter does not even have a Health Care Card or Disability Support Pension because until recently she was technically employed while using up her accumulated leave. Therefore I am handling all her superannuation, financial planning and tax matters while juggling with the NDIS.

I am proud that despite all her health problems she worked full time and travelled to the city daily until her last stroke. It is galling though that so many people seek to abuse the NDIS and other government benefits. Please accept my apologies for the length of this submission. I have given you hard facts but also I hope a sense of what it means to the people suffering from disability who are unable to speak for themselves.

Finally I will reiterate this point. Most, if not all, people in the health system do their level best and sometimes more. That certainly applies to the _____ and _____ .. However when you are present daily as I am you see things happen or fail to happen which are unacceptable, and not in accordance with required standards.

Despite the best of NDIS intentions it is the outcome which is important. In some cases it is about human and financial resources, but it is often about systems and processes and lack of political understanding.

Yours sincerely